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I Am a Citizen: An Examination of The Civic Lives of Adults with Cognitive Disabilities.

Jihed Ncib, *Eastern Illinois University*

THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF ARTS IN POLITICAL SCIENCE

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2019

Abstract: This project lays down a foundation to study the civic lives of people with cognitive limitations. Considering the lack of research on the issue, the findings lean more toward theory building. Drawing on in-person interviews conducted with institutionalized individuals with intellectual disability (ID), this work attempts to clarify the impact of their disability on their civic lives. The questions that will be answered relate to their issue preferences, voting behavior, partisanship and mobilization, political awareness, and the influence of their circle on their citizen participation. Getting input directly from people with ID, instead of their proxies, will improve our understanding of their political (or lack of) involvement.

Dedication & Acknowledgment

Mom, Dad, Rajaa, and Ameni, you're my inspiration and the pillars that hold my life. You believed in me and supported me at every turn. All I am, or hope to be, I owe to you.

Dr. Paul Danyi, you've been a friend and a mentor. If I become only half the scholar that you are, it will certainly be one of my greatest achievements.

Friends in Tunisia, France, and the U.S., you shaped the person that I am today. It has been an honor getting to know you throughout this journey.

Thank you

Merci

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Introduction

"I should have a say"¹

Clinton Gode's struggle to have his voting rights recognized by the state of Arizona was featured on national news. He thought that Down Syndrome should not be an excuse to deprive him of his rights as a citizen. The federal Voting Rights Act² states that mentally incapacitated people may be stripped of this right. Such restrictions are often justified by the need to prevent voter fraud and to ensure that cognitively impaired individuals are not manipulated into voting for other people's preferences (Holland et al., 2011). This is also due to the fact that decision-making and evaluation skills are regarded as inherent requirements for self-determination (Wappett, 2002). Clinton's case, among many others, defies these beliefs. "I am a voter", he says. When his sister reached the voting age, he was excited and expected that he too would be able to participate one day. However, his placement under legal guardianship prevented that from happening. Clinton considers himself self-sufficient as he no longer lives with his family and earns his paychecks. Along with his parents and several advocates, he took it upon himself to convince Arizona lawmakers to change the status quo. By virtue of this mobilization, intellectually disabled people in Arizona can petition the court to recognize their voting rights. Clinton stood before a judge who had to assess his ability to cast a ballot. When asked if other people tell him how to vote, he replied, "Yeah, but I don't listen to them." Clinton voted for the first time at the age of 25. "I am very, *very* proud of that", he said as he showed his voter-registration card.

¹ Karina Bland - Oct. 27, 2012 11:00 PM The Republic | azcentral.com. 2012. "Against Long Odds, 1 Man, 1 Vote." azcentral.com. <http://archive.azcentral.com/arizonarepublic/news/articles/2012/10/17/20121017against-longodds-man-vote.html?fbclid=IwAR2ieJ1Kd19vRJmYxQx-fb05kgb5R1y7nTVId15uyn45o1uEILTIHMgvF2E> (October 25, 2019).

² The U.S. Voting Rights Act. 1965.

However, Clinton's success story cannot be generalized. Adults with intellectual disability (ID) in different parts of the world still face limitations to their voting rights. "The electoral commission has been unable to confirm that you understand the nature and significance of enrolment and voting."³ was the response that Shea, an Australian who has Down Syndrome, received. Despite having a university education, Shea was unable to participate in elections. "I demand my right to vote", she says.

This struggle is not unique as advocates everywhere call for the repeal of disenfranchisement laws around the world. These statutes tend to treat the mentally disabled as a bloc and not using a case by case approach. The examples of Clinton and Shea demonstrate that intellectually disabled individuals can be politically aware. The American Association on Intellectual and Developmental Disabilities defines ID as "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills."⁴ And intellectual impairments have different levels of severity and can range from mild to severe (Boat, 2015). Thus, it would not be opportune to make generalized laws that do not take into account the capacities of each individual.

The challenges faced by adults with cognitive limitations extend beyond voting and include multiple areas of civic life. They are usually uninformed about political issues and they cannot easily find suitable materials that make them acquainted with relevant matters (King and Ebrahim, 2007). In a research conducted by Agran and Hughes (2013), a parent of an adult with ID states, "our experience was that the adult provider where my daughter lived/worked for a while did not make it important, nor did they take the time to educate the residents about the issues and

³ Gorman, Ginger. 2017. "Down Syndrome Woman Denied Right to Vote." NZ Herald. https://www.nzherald.co.nz/world/news/article.cfm?c_id=2&objectid=11925558&fbclid=IwAR1SQgG7iv3K60YP1briFHmsSUuWM2_nh1JPDjYvcsvQq-GBrTa62vrMDM (October 25, 2019).

⁴ "Definition." 2019. Aaidd.org. <https://aaidd.org/intellectual-disability/definition> (27 September 2019).

candidates." Additionally, public institutions do not provide them with sufficient support to advocate for their issues (Friedman, 2017). Political actors also remain resistant to adapt their approaches to the needs of this group or to enact public policies that would promote equal citizen participation (Lussier-Desrochers et al., 2017; Foster and Boxall, 2015).

Cognitive impairment has long been viewed as a reason to exclude people not only from civic and political involvement but also from basic concepts of citizenship (Carey, 2003). Hence, voting might be the visible tip of the iceberg that captures the media's attention. Intellectually disabled people face many hurdles in their daily lives that extend to their ability to represent themselves. Previous studies on the issue indicate that self-advocates with ID often complain about society considering them unrepresentative (Beresford and Croft, 1993). Consequently, their proxies, such as parents or caretakers, were considered more suitable to represent them. These views also affected the research field, which constitutes a critical weakness of the existing literature on the issue. Few studies sought to get input from the intellectually disabled. Instead, they often rely on the perspectives of people in their circle (Sigstad, 2014; Agran and Hughes, 2013). As a result of this stigma, people with cognitive impairments are under-represented on disability advisory bodies (Frawley, 2008). Meaningful participation and advocacy are yet to be achieved due to the lack of accessibility and support (Whittell and Ramcharan, 1998).

Legal framework

International law is an area where several legal guarantees were enacted to ensure the inclusion of this demographic. For instance, the UN Convention on the Rights of Persons with Disabilities has been signed by 162 states. The United States, however, signed the convention but never ratified it. This convention is a compelling example of the change that took place regarding people with disabilities in the beginning of the 21st century. It lays down several measures that aim

at protecting disabled people and ensuring their equality under the law. The provisions of this convention cover several rights including political ones. Article 29 states that "Parties shall undertake to ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected."⁵

Regional organizations have also adopted legal instruments that reinforce the protection and the inclusion of disabled individuals. For instance, the European Union's Charter of Fundamental Rights affirms that "The Union recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community."⁶

On the national level, the U.S. federal government has enacted the Americans with Disabilities Act of 1990. This civil rights law shows the anti-discrimination efforts that have been made to ensure that disabled people receive equal treatment.

However, several countries still maintain statutes that go against the guarantees laid down by international law. A study conducted in 2016 revealed that disenfranchisement is still occurring in a large part of the world. The authors found that "twenty-one states maintain no suffrage restrictions for mental illness, sixty-nine states disenfranchise all people with any mental health problems without any qualifier, nine states disenfranchise people detained under mental-health laws, and fifty-six states authorize courts or magistrates to disenfranchise people for mental-health reasons" (Bhugra et al. 2016, p. 396).

In the U.S., courts are still allowed to consider an individual unable to vote based on their intellectual capacities. The constitutions of nine US states allow the automatic disenfranchisement

⁵ Convention on The Rights of Persons With Disabilities (CRPD). 2006.

⁶ Charter of Fundamental Rights of the European Union. 2000.

of mentally incompetent people. Several other states only allow this restriction when a judge considers the person incapacitated under the spotlight during recent electoral campaigns. It is also difficult to specify the number of Americans who are deemed ineligible to vote due to incapacity.

This project lays down a foundation to study the civic lives of people with cognitive limitations. Considering the lack of research on the issue, the findings lean more toward theory building. Drawing on in-person interviews conducted with institutionalized individuals with intellectual disabilities, this work attempts to clarify the impact of their disability on their civic lives. The questions that will be answered relate to their issue preferences, voting behavior, partisanship and mobilization, political awareness, and the influence of their circle on their citizen participation. Getting input directly from people with ID, instead of their proxies, will improve our understanding of their political (or lack of) involvement.

Guiding questions

This project seeks to examine the political behavior of cognitively impaired individuals. It attempts to answer questions related to their participation and goes beyond the limited existing literature. Thus, it leans more toward theory building via observing their behavior, interpreting it, and explaining the reasons behind it. Exploring the influences that define political positions, ideologies, and the level of involvement of people with ID will be at the center of this study. The literature on this issue solely focuses on voting behavior and rarely attempts to explain the reasons behind it. Previous studies essentially address voter turnout neglecting other aspects of civic life (Keeley et al., 2008; Schur et al., 2002). Besides, the broader literature on disability and citizen participation either treats both physical and intellectual impairments as a whole or fails to include people with ID (Rak and Spencer, 2016; Hästbacka et al., 2016; Stienstra and Troschuk, 2005; Checkoway and Norsman, 1986).

This research was guided by multiple questions. People's political behavior is often affected by their daily lives and experiences and the cognitively impaired are no exception (Reher, 2018). Thus, it is useful to examine this group's issues of importance. Verifying whether these preferences relate to their experiences as intellectually disabled individuals would offer insight into their civic lives. Moreover, when it comes to voting behavior, their turnout rate is not the only significant information. The barriers that they face on election day, the role of the person that aids them in casting their ballots, and the influence of their circle are also important aspects to ask about. I also assess the validity of the arguments used to support their marginalization. Hence, I will attempt to answer questions related to their political awareness and their ability to cast a logical and informed vote. Other aspects covered by this project include partisanship, mobilization, sources of information, and the impact of the severity of disabilities.

Literature Review

Conceptualizing cognitive limitations

Clarifying the concept of intellectual disabilities is crucial to have a better understanding of the political behavior of the cognitively impaired. Predictably, most research on this question comes from the field of psychology. In order to diagnose someone with an intellectual disability, experts need to base their verdict on an intellectual assessment (MacLean et al., 2011). However, this type of limitation is also affected by socio-cultural factors. How people in a given society perceive individuals with cognitive disabilities tends to affect the concept itself. For instance, in Filipino culture, these disabilities are perceived as originating from supernatural powers (Brolan et al., 2014). The same literature points out that, in the Philippines, families tend to prefer folk healers over proper medical assistance. Several other examples demonstrate how these social factors shape the concept of intellectual disability. During the industrial revolution, intellectually

limited people were deemed less effective and less functional, which resulted in their alienation (Titchkosky, 2009). And the legal system reflected these views considering that people with ID were often presumed legally incompetent to vote (Bell, McKay, and Phillips, 2001).

However, this concept evolved throughout the decades of (WHEN?). This development "encompasses an increasingly integrated approach to ID, especially regarding shared aspects such as limitations in human functioning (i.e., disability), a focus on the human and legal rights of persons with a disability, the eligibility for services and supports based on significant functional limitations in major life activity areas, and an emphasis on individualized support provided within inclusive community-based environments (Schalock, Luckasson, and Tassé, 2019, p. 223)."

Furthermore, the terminology used to describe these impairments changed with the advancement of research. One can see that it became more "politically correct." The previously mentioned definition provided by the AAIDD is generally adopted by the literature. However, scholars highlighted the need to join it with five assumptions to make it more operational: limitations in functioning must be considered within the context of community environments typical of the individual's age peers and culture; valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors; within an individual, limitations often coexist with strengths; an important purpose of describing limitations is to develop a profile of needed supports; and with appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve (Wehmeyer, 2013).

The terms used in early works were considered insensitive and negative. For more than half a century, American literature on people with ID employed terms such as "retarded" and "idiot" (Keith and Keith, 2013; Harris, 2006). Hence, scholars have considered that the modern

era has brought significant positive changes in the lives of people with intellectual disability (Wehmeyer 2013). Taking into account their considerable impact on individuals, these labels had to be changed and the literature shifted toward a “medical model of disability” (Memari and Hafizi, 2015). The old terminologies contributed to enforcing stereotypes about people with cognitive limitations and were used "as a form of abuse" (Hayes, 2010, p. 35). Considering that socialization entails the process of internalizing the norms of society (Campbell, 1964), the self-discrimination of these individuals was an obstacle to overcoming marginalization. This stigma affects the identity of the intellectually disabled and contributes to shaping it; and it resulted in the deterioration of the perception of this minority group. A study on Taiwanese young people with cognitive disabilities showed that their feelings of stigmatization emanated from these labels. These connotations changed their perception of themselves and led them to isolation and avoidance (Chen and Shu, 2012). More broadly, this also applies to other minority groups, including those based on sexual orientation (Coleman-Fountain, 2014).

Granting that disability is often perceived as a construct, models of "thought and action" lead to a better understanding of this concept. The medical model entails that disability could be reduced by understanding its origins. It constitutes a discontinuance with the traditional models that regard disabilities through a charity or a traditional approach. Instead, these limitations are seen as medical issues "via the perspective of non-disabled people and experts" (Smith, 2005, p. 561). It is regarded as the main approach to study not only intellectual disabilities but also other types of impairments. However, this model is often criticized for being too pragmatic and, thus, neglecting the social aspects of disabilities (Filc, 2004). This explains the emergence of the social model that considers that disability is "created by a society that disables impaired people" (Oliver, 2009). It views disability not as an illness but as a "long-term social state." Thus, disability turns

into a social construct under this approach. Some scholars even called disabled people to engage in class struggle as the only way to change the nature of society and how it views this group (Finkelstein, 2001). However, a major criticism of this model results from its origins. The social approach was initially formulated around solely physical disabilities. This has led to the absence of sense of shared ownership and collectivism of this model (Barnes and Mercer, 2004). Several other models have emerged such as the eugenic model (Galton, 2019) or the charity model (Stiker, 2000). However, the medical and the social approaches had more impact.

Previous research on intellectual disability and political involvement

Due to the advocacy of both disabled and non-disabled people, the efforts supporting DI involvement in civic life have increased. However, as a disadvantaged group, cognitively impaired individuals still face barriers regarding participation in the political process. One neglected area of services provided to people with ID is citizenship, specifically voting (Agran, 2015). Voting is the area that scholars strongly, if not near exclusively, focused on. This civic duty is regarded as a right that is granted to every citizen without any discrimination. However, the literature developed in the following sections suggests that the intellectually disabled are often excluded from community life. Therefore, it is be interesting to see if that affects ID civic participation.

Several studies attempted to assess the participation of individuals with ID in the democratic process by casting their ballots (stack them here). Quantitative scholars have conducted a variety of surveys to determine the level of this involvement. The findings demonstrate that cognitively impaired people understand the concept of voting and its consequences and that they have an interest in it (Martin Agran, MacLean, and Kitchen, 2016). For instance, survey results related to the 1976 presidential election show that the number of intellectually disabled voters was relatively high, which urges legislators to remove any obstacles to their participation (Olley and

Ramey, 1978). The largest study available surveyed 1341 people and revealed "significant relationships between voting participation, and support needs, residence types, guardianship statuses, and organizational supports" (Friedman and Rizzolo 2017, p. 347).

Qualitative studies have also been published, often relying on interview methods. Obtaining information directly from cognitively disabled people turn out to be very informative. Some show, for instance, that support from family or caretakers and self-advocacy encouraged them to vote (Agran and Hughes, 2013). It also highlighted some of the barriers faced by these individuals such as the lack of education on political issues or on how to make voting decisions (Martin Agran, MacLean, and Kitchen, 2016).

Some of these studies were country-specific, which could reveal the eventual disparities and variation across different contexts. Recognizing that culture play an important role in conceptualizing intellectual disability (Brolan et al., 2014), it is useful to examine this phenomenon in different parts of the world. In a study based in Sweden, 20 intellectually disabled individuals were interviewed regarding the Swedish general elections between 1998 and 2006 (Kjellberg and Hemmingsson, 2013). The results showed that the majority of participants cast their ballot. But they also suggested that age was the main factor. Kjellberg (2013) asserts that the development of Swedish social policy played a positive role considering that "people born during the 1940s and 1950s voted more often than people born during the 1960s and 1970s. (Kjellberg, 2013, p. 326)" A study in the United Kingdom compared the cognitively impaired electorate to the rest of the population and showed that the former participated significantly less than the latter (Keeley et al., 2008). It also showed the importance of living conditions as living with another active voter seemed to be a positive indicator but also those who live in supported housing were more likely to vote. Other scholars focused on the impact of technological advances on their voting behavior.

After the introduction of mobile polls in Israel in 1996, a study revealed that only a third of cognitively impaired people voted compared to two-thirds of the rest of the population (Melamed et al., 2007). Those who voted reported positive subjective feelings such as responsibility and pride.

Other work has focused on specific diagnoses and used these diagnoses as independent variables. For instance, scholars have studied the voting characteristics of people with traumatic brain injury and examined the interaction between voting and other variables such as marriage, which was inversely related to voting (Hirsch et al., 2019). Other specific impairments were also studied such as Dementia (Karlawish, 2008) or Down Syndrome (Barclay, 2013).

Scholars also attempted to identify the barriers faced by people with ID and recommended possible solutions to overcome these hurdles. For instance, "many polling places are still inaccessible and election officials have little or no knowledge of how to accommodate people with intellectual impairments" (Ward et al., 2009, p. 82). These studies indicate that accommodations for people with intellectual disabilities are often not understood. This confirms the previously stated literature that says that this group does not get to shape its own experience (Caldwell et al., 2009). Moreover, several other barriers were highlighted such as the lack of identification documents (Melamed et al., 2007) or the absence of voting instructions (Agran, 2015).

These studies have improved our understanding of the voting behavior of cognitively impaired people and the difficulties that they face. However, most of these works focus exclusively on elections and voting (Agran et al., 2016; Keeley et al., 2008; Schur et al., 2002). Whereas political behavior includes several other aspects that the existing literature ignores (Conge, 1988). For instance, the motives of their voting choice, issue importance, political awareness, and partisanship.

Further, the influence of their circle on their political involvement is a question that has not been sufficiently addressed. The vulnerability of these individuals makes them more exposed to outside influence (Fisher et al., 2016). And only a handful of studies tackle this issue. A large portion of people with ID are institutionalized and/or live in supported housing, which means that they might be subject to the influence of multiple actors.

Additionally, there is a lack of research on the topic generally by political scientists. Most of the literature that treats this issue comes from fields such as psychology or special education, including the ones that are related to voting (Kamens et al., 2019; Capri et al., 2018; Agran et al., 2016; Davis, 2010; Bullenkamp and Voges, 2004). The psychological perspective is certainly helpful, however, political science and the literature on political behavior contain useful frameworks and models that can be brought to bear upon the question of participation, or civic lives, of the cognitively disabled (Clinton et al., 2018; Hassell and Settle, 2017; Burden et al., 2016; Pacheco and Fletcher, 2015). Additionally, much of the literature related to the civic lives of people with ID took the form of legal analyses (Kopel, 2017; Ryan et al., 2016; Lord et al., 2014) that lack the benefits of empirical inquiry.

People with ID as a disadvantaged group

Social sciences have looked at society as a hierarchy of groups that interact with each other. These complex relations are often characterized by inequality and the dominance of one portion of the population (Fischer et al., 2012). In this context, scholars have indicated that class struggle has intensified during the modern era (Webber, 2017). Different social groups do not enjoy the same level of privilege. Hence, disadvantaged demographics often lack the tools provided to the dominant group in what is called inequality of conditions and inequality of opportunities (Wormald et al., 2019). Inequality of conditions refers to the unequal distribution of material goods and

having poor minority neighborhoods is a compelling example of this. Whereas inequality of opportunities refers to the unfair attribution of life chances.

The muted group theory has been developed to describe the disparity of power between social groups. It entails that the dominant group restraints the potential of subordinate groups mainly via the use of language (Ardener, 1975). As mentioned earlier, intellectual disabilities were referred to using terms that reinforce stereotypes. This power of naming (Kramarae et al., 1984) constitutes an effective tool to marginalize minority groups because it affects their perception of themselves. This theory focuses on how the dominant group exclusively holds the ability to name experiences (Wood, 2005). For instance, using negative connotations to refer to members of racial groups has been a major issue throughout the decades.

The muted group theory was initially developed by feminist literature to describe how men mute women through the dominant discourse. However, scholars have affirmed that this also applies to any group outside of the mainstream (Orbe, 1994). Thus, one could consider that this muting process includes minorities based on race, sexual orientation, but also disability. The marginalization of these subordinate groups occurs through different means including "repeated silencing over time and silencing through the ambiguity of policies" (M. M. Meares et al., 2004, p. 17). Prohibiting these individuals from conceptualizing their own experiences would certainly result in their alienation. This misrepresentation of experiences is viewed as a way to reinforce the control of one single group over the others by determining how they view their own experiences. This explains the criticism received by the medical model of disability knowing that it is based on the conclusions of non-disabled people.

Socialization entails adopting behavior that is acceptable to society; and if the dominant group has a monopoly over the determination of these norms, minority groups will eventually

accept the status quo because identity and reality are socially constructed (M. Meares, 2017). Disabled people, as a muted group, are not given the chance to shape how society views them. Thus, they are forced to change their thoughts and activities to make them align with social norms (Nangabo, 2015). Calvez (2001) argues that "what makes disabled people muted is that claims of its members to participate in social life are discounted and that they have internalized the idea that they are not entitled to raise their voice. (Calvez, 2001, p. 51)" This is also achieved through the use of pejorative terms such as "retard" that ridicule and even harass disabled people (Stiker, 2000).

Other theories have also put the spotlight on the hierarchical structure of society. The social dominance theory asserts that group-based dominance is a result of discrimination on different levels: institutions, individuals, and intergroup processes (Pratto et al., 1994). This approach also considers that this hierarchy results in an unequal distribution of power among social groups. Scholars even suggested that tendencies of social dominance appear in early childhood and develop throughout the lifespan (Pun et al., 2017).

Ableism, the discrimination in favor of able-bodied people, was perceived as a result of this social dominance model (Kattari, 2015). In this context, the literature developed a measuring scale that determines the level of social dominance in individuals. For instance, it assesses people's agreement with statements such as "sometimes other groups must be kept in their place" and "it's probably a good thing that certain groups are at the top and other groups at the bottom" (Pratto et al., 1994, p. 763). This approach can be employed to study intra-group interactions based on several variables including disability, gender, or race. Sidanius considers that a hegemonic group is present on top of every society and that it develops myths and ideologies that intensify the social hierarchy (Sidanius and Pratto, 1999). Stereotyping disabled people as incompetent and dependent

illustrates these assertions. Thus, this theory suggests that members of the dominant group will try to allocate resources based on their self-interest at the expense of members of subordinate groups.

The concept of “ableism” was used by scholars to capture the discrimination against people with ID which puts the individual in a disadvantaged position. In different aspects of their lives, disabled people are perceived as less competent and that able-bodied people are more reliable. Thomas Hehir (2002) defines ableism as "the devaluation of disability"; and in the education field, for example, it "results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with nondisabled kids as opposed to other disabled kids (Hehir, 2002)". This leads to viewing disability through the lens of ableism and, thus, the impairment is signified instead of the disabled identity (Loja et al., 2013). This "abled" narcissism (Campbell, 2012) has been an obstacle to overcome stereotypes and to view disabled individuals as equals. It constitutes a challenge not only for the disabled but also for their families. For instance, parents viewed their roles in the community as advocating, educating, informing, ignoring, and hiding (Barnes and Mercer, 2004). Thus, ableism is arguably as harmful as sexism or racism (Harpur, 2009). It has negative consequences on individuals' health and well-being (Branco et al., 2019) and considers that ability is a valid reason to discriminate and practice negative differential treatment (Dirth and Branscombe, 2019).

Disability and social inclusion

As previously stated, modern societies are still hierarchical and even subtly segregated. Vulnerable populations such as people with intellectual disabilities are still stereotyped and, thus, often excluded from their communities. Studies have shown that individuals with cognitive limitations are more likely to suffer from loneliness in their lives (McVilly et al., 2006). This

suggests that the "abled" portions of society tend to avoid interacting with them. Such exclusion has an impact not only on the self-perception of people with ID but also on their willingness to be active in their communities (Merrells et al., 2017). However, it is also suggested that not all intellectually disabled people are exposed to the same level of loneliness. Several factors determine whether a person is included. For this particular demographic, it was suggested that dependency is the key variable (Wormald et al., 2019). More dependent people are more likely to be excluded. One could infer from such findings that social inclusion depends on the severity of the person's disability knowing that those who are more independent are more likely to have low to mild disabilities.

McConkey (2014) attempted to assess the effect of the place of residence on the inclusion of this group. They found that "the best predictor of this was the individual's level of dependency in personal self-care" (McConkey et al., 2005). Moreover, non-disabled prospective neighbors of people with challenging behaviors often base their impressions on the size of the group moving in and on the severity of the intellectual disability (Dijker et al., 2011). It also seems that this lack of inclusion is caused by other social groups because people with intellectual disabilities want to socialize, have friends, and be a part of their communities (Wilson et al., 2017). This exclusion can have negative consequences on members of this group. It can increase their vulnerability, for example, as marginalization can leave them exposed to mistreatment and abuse. For instance, scholars suggested that intellectually disabled people face several barriers to reporting sexual assault that include fear, communication, sexual knowledge, lack of resources, and misconceptions (McGilloway et al., 2018).

Social inclusion has been inadequately addressed not only by states and society but also by scholars. It has been poorly defined and measured (Bigby, 2012). It has also been found that several

obstacles prevent people with cognitive limitations to participate in research including taking surveys. For instance, engagement with precision medicine studies, that propose a customized healthcare, is low because they do not resonate with the interests and needs of this population (McGilloway et al., 2018). Furthermore, research funding itself often requires the inclusion of people with disability but this inclusion is not well-executed by researchers themselves. This lack of understanding has led to minimizing its impact on the academic field; whereas it could have a positive outcome if it is seen as a collaboration (Frawley and Bigby, 2011). Including researchers with intellectual disability in study teams would not only benefit them but also the potential of research as it was found that this inclusion is both meaningful and feasible (Goldsmith and Skirton, 2015).

This exclusion can also be observed in other areas. For instance, the inclusion of intellectually disabled students has been a major concern in society. During their young age, disabled individuals are considered more vulnerable and easily influenced and they often lack the ability to initiate and maintain social relationships (Gresham and Elliott, 1989). Thus, it is important to create an atmosphere where they can engage and interact with their non-disabled peers. Yet the literature indicates that disabled students are more prone to segregation and exclusion than others and that they are more likely to have imaginary companions (Snipstad, 2018). Furthermore, organizational constraints, inadequate facilitation, and lack of self-confidence among students were identified as challenges (Sigstad, 2018). This shows the importance of inclusion in schools considering that this experience shapes the child's identity throughout their life (Garbrecht, 2006).

Additionally, intellectually disabled individuals often face difficulties in transitioning to professional life. If done successfully, their inclusion in the workplace could have a positive impact

on them. It would aid them in becoming more independent and autonomous and would increase their self-satisfaction (Silva, 2018). But the success of this inclusion depends on several factors. For instance, it was found that top management commitment plays an important role (Maini and Heera, 2019). This social exclusion is directly related to political marginalization. Citizen participation requires an immersion in community life. Thus, alienating people with ID would certainly lead to lower civic engagement.

The role of gatekeepers

Political behavior is shaped by individuals' experiences and their circle (Egan and Mullin, 2012; Suárez, 1998). And these experiences often involve people in their circle. One cannot study the cognitively impaired without examining the influence of those who surround them. Guardians are an example of these people as they hold a legal authority to make decisions in place of the vulnerable person. This puts a significant power in their hands. Even in the absence of guardianship, disabled people could still be influenced by family members or their service providers. Such factors explain the legitimization attempts of disenfranchisement laws based on the need to protect the integrity of elections. Intellectually impaired people can be influenced and manipulated especially when they lack the capacity to understand the meaning of voting (Doron et al., 2014). Even when it comes to conducting research on this population, it was found that parents hold the ultimate decision to allow the disabled person to participate (Collings et al., 2016). Moreover, intellectually disabled participants in research projects are usually recruited via gatekeepers (Goldsmith and Skirton, 2015). This recruitment is very important considering that obtaining direct input from the disabled person, despite its challenges, is more beneficial than interviewing their proxies. This strengthens the quality of research, but it should be done with careful consideration of methodological and ethical issues (Gjertsen, 2019).

These gatekeepers play an important role in shaping an individual's identity. For instance, guardians often act as accountants, legal advocates, and in some cases surrogate family members (Giertz, 2018). And their task is not easy considering that they have control over a person's life. They face challenges in fulfilling their role and get better at it with practice and forming practical strategies (Bigby et al., 2017). Besides, this task has a negative impact on these caretakers due to the complexity of its nature (Gjertsen, 2019).

Acknowledging that taking care of disabled people has such an important impact on the caregiver, this influence could be reciprocal. Gatekeepers are viewed as authority figures that have a say in the lives of people with ID which could include its civic aspect. Thus, it is interesting to examine the extent of this influence and whether it affects the integrity of the democratic process.

Research design

For the purpose of this study, semi-structured interviews were conducted with individuals with cognitive limitations to obtain insight into their political behavior and awareness. This method was chosen due to the lack of survey data on this demographic and the difficulty in generating representative, random, samples for this specific and relatively small group in society. Moreover, interviewing these individuals is the most reliable method to gain a deep understanding of their experiences. These qualitative approaches are suitable especially when the research aims at ascertaining and theorizing prominent issues (Jamshed 2014). This method proved to be particularly effective in this project considering that semi-structured interviews "allow the researcher to collect open-ended data, to explore participant thoughts, feelings and beliefs about a particular topic and to delve deeply into personal and sometimes sensitive issues" (DeJonckheere and Vaughn, 2019). According to Sigstad (2014), conducting interviews with intellectually

disabled people presents particular research challenges. This author offered detailed guidelines that were followed in this project to ensure the accuracy of the findings.

Convenience sampling was employed due to the complexity of collecting data on people with ID. One of its major weaknesses is not being representative of the entire population. Furthermore, recruiting participants was also a source of concern. Individuals voluntarily agreed to participate. Especially in the case of people with ID, such an approach could eliminate those who did not volunteer due to social anxiety for example. However, I do not believe that this issue will have a major impact on the findings. The purpose of this project is not to create predictive models of behaviors of people with ID. Instead, it aims at explaining how these behaviors occur and, thus, building a foundation on which future studies can rely.

Participants

The in-person interviews were conducted with 20 participants: 8 women and 11 men with cognitive limitations and some further insight was obtained from their counselor(s). Participants' ages ranged between 32 and 67 (mean = 48.30); and they were all of white ethnicity with the exception of a half-Mexican participant. 18 participants were not under any form of guardianship which enabled them to sign the consent forms themselves. Only one participant was required to provide the signature of their guardian. Interviewees resided in central Illinois and they had different types of intellectual impairments joined with physical disabilities in some cases.

A local not-for-profit corporation was contacted by the investigator and its staff agreed to provide help. Its mission is to provide community-based services and to enhance the quality of life of citizens with developmental disabilities and other functional limitations. Several clients of this facility are also employees of the corporation. They also spend most of their free time inside the

facility with their peers under the supervision of different counselors. Interviewees were offered the chance to take part in this study and they voluntarily agreed.

Due to medical privacy concerns, the specific impairment of each participant was not divulged. However, the corporation provided a general list of impairments that they deal with. The most common developmental diagnosis is Intellectual Disability (mild, moderate or severe). To qualify for the corporation's adult services, individuals must have an intellectual disability or related condition that manifests before the age of 22, is likely to continue indefinitely, and results in substantial functional limitations in major life activities. Beyond the primary diagnosis, individuals have a wide range of secondary diagnoses such as Down Syndrome, Schizophrenia, Impulse Control Disorder, Diabetes Mellitus (type 2), Mood Disorders (Major Depressive Disorder, Bipolar Disorder, etc.), Attention-Deficit Hyperactivity Disorder, Hypercholesterolemia, Epilepsy, Hypertension, Autism Spectrum Disorder, and Sleep Apnea.

Procedures

The interviews were scheduled by the corporation's staff depending on each participant's availability. All participants who signed the consent forms appeared for the interview with the exception of one participant who was unable to appear due to health reasons. All interviews were conducted by the same researcher who is also the author of this thesis. The face-to-face interviews lasted between 15 and 45 minutes and took place inside the facility. All but two interviews were conducted individually. Due to the severity of the disability of two interviewees, the assistance of a counselor was required. The interviews were recorded using a digital device and were later transcribed. At the beginning of each session, the study was explained to the participants and they were informed of their rights which include anonymity and the possibility to withdraw their consent at any time. Participants were also asked to provide personal information such as age and

marital status. The content of the interviews was based on open-ended questions related to their political awareness, issue importance, voting behavior, gatekeepers and their political involvement, and sources of political information. The present project was approved by Eastern Illinois University's Institutional Review Board.

The difficulty surrounding the process of interviewing cognitively impaired individuals

Several challenges were faced during these interviews due to the interviewees' disabilities. First, each question had to be formulated in a particularly simple manner to make it clear and comprehensible to them. This task is particularly challenging when the questions relate to the political field. Second, several difficulties arose with participants who have a severe disability. Some of them had a very short attention span which made it challenging to stay on topic. Others were unable to communicate well to the point of giving unintelligible responses. Furthermore, several participants were unable to formulate developed answers. This was particularly challenging considering that the investigator's role in semi-structured interviews is to allow the interviewees to express themselves without guiding them.

Interview analysis and coding

The coding framework was essentially based on constant comparative methods of qualitative inquiry. It entails comparing each finding with the existing ones that emerged from the analysis. This method is particularly efficient to study issues that "raise problems of secrecy, sensitivity, taboo topics, stigma, and legality" (Glaser, 1965) because it involves "a combination of observing what is going on".

ATLAS.ti, a qualitative analysis software, was also employed to arrange and manage interview materials in a systematic manner. Recordings of the interviews were transcribed and analyzed using this software. Several themes emerged from this analysis and the content of the

interviews was classified into different sections. Thus, participants' responses were assigned to different categories. This thematic approach will be reflected through the different sections of this project.

Apart from traditional methods of content analysis, the data were also analyzed using RStudio, an integrated development environment for R programming language. A dataset was built to explore the guiding questions through a statistical approach. It contained categorical variables such as levels of disability and living accommodation and dichotomous ones such as voting and recognition of public officials. Furthermore, Tidytext, an open-source R package, was employed for the content analysis. Different patterns and trends in the interviews were discovered through this text data mining process.

Findings⁷

"I love politics."

Political awareness is a wide-ranging concept that has been extensively discussed in the literature. It is a polysemantic term that could also be referred to as political sophistication or knowledge. Broadly, political awareness designates the amount of information that an individual has about politics (Delli Carpini and Keeter, 1996). It comprises multiple facets that include political interest, information, and acquaintance. Other definitions of this term present it as the intersection of interest, participation, and knowledge (Fiske et al., 1983). Civic participation entails a basic understanding of the democratic process. For this participation to be effective and constructive, individuals are expected to be familiar with the political system and its functioning (Niemi and Junn 1998). This sophistication is often considered as one of the main indicators of political involvement (Converse 2000; Luskin 1990).

⁷ (For confidentiality purposes, participants were assigned different pseudonyms.)

As the previously discussed literature suggests, cognitively impaired individuals are often deemed not informed enough to take part in civic life. Hence, exploring the extent to which people with ID are familiar with the political sphere could be a predictor of their participation. Throughout the interviews, general open-ended questions were asked to assess this knowledge. This type of questions allowed participants to develop their responses without being guided or directed to a specific area of politics.

The first aspect of political knowledge was the recognition of political figures. First, interviewees were shown a picture of the American president and asked to identify him. 15 out of 19 participants managed to correctly name him and the position that he holds. Some even mentioned details about him outside of his political involvement. Whereas two participants identified him as the president but were unable to recall his name.

"He's the current president, Donald Trump. He became president in 2016. He had a TV show."

— Daniel

"I know President Trump. Did he get in trouble one time? A girl or something? I heard about that." — Edward

"I can't think of his name. He's the president" — Chloe

Second, interviewees were asked if they know other politicians and details about them. The majority of participants gave developed answers. Sarah, for instance, noted, *"I like Hillary because she would be nice in the office. I don't know if she's running this year or not."* Most responses revolved around major figures on the national level. Emily, a female in her early thirties, stated, *"Obama seemed like he could do a great job. Other people don't like him, like Trump. He tells him you're not born in the United States."* Ethan, a male in his late fifties, talked about former presidents and what he knows about them, *"Obama was a Democrat. He was a good guy for eight*

years [...] Bill Clinton was alright too. Bush too, the one that passed away. He was all right. The bad one was Nixon, the Watergate. He was a crook."

Participants were also asked about recent events that are related to politicians that they mention. Their responses did not only demonstrate a relatively solid knowledge of politics but they also showed their ability to formulate stances regarding political issues. The majority of the sample managed to develop thoughts and attitudes about ongoing political matters.

"I think years ago one of the governors was in prison. I think it was Ryan." — Sarah

"He separated the immigrants, detained them. I saw it on TV. If I did that, I would probably be in trouble." — Amy

"He put tariffs on Chinese goods. A lot of stuff comes from China. I have mixed feelings about him [...] He also likes Kim Jong Un." — Emily

Political institutions were also among the topics that the interviewees discussed. In these cases, the investigator followed up with questions that seek to assess their familiarity with the political system. Overall, participants demonstrated basic knowledge of the functioning of the government. Hannah, for instance, reflected on the recent impeachment calls in Congress. Her responses indicated that she understands the concept of impeachment and its consequences. When asked about general views toward politics, she stated, *"Whenever I hear the word politics, I think about the Constitution. I know the beginning of the Constitution; 'We the People'."* Furthermore, Daniel, a participant in his early thirties who also has a physical disability, noted, *"The government makes the laws. I heard about the law where you can't drive and use your cell phone. The Senate and the Congress run the government. They help make the laws."*

Yet, some respondents gave statements containing false factual information. This observation, however, was only limited to two interviews. Amy, for example, thinks that Hillary

Clinton is a part of the Illinois state government. Moreover, this point should not be amplified as the literature suggests that false facts exist even among the general population (Allcott and Gentzkow, 2017). As to the outliers, only three interviewees were not as knowledgeable as the rest of the sample. The level of disability could be a factor in this case as two out of the three participants had severe cognitive impairments. Besides not being aware of recent events, these outliers indicated unfamiliarity with certain terms such as politicians and government. Harry, a participant in his late thirties, said, *"I don't follow what's going on in the country. I don't have cable. I have internet but I can't read."*

Overall, responses indicated a certain degree of political knowledge among the sample. Zaller (1990) asserted that people who are low on political awareness often answer survey questions with "no opinion." Whereas most responses in this study reflected relatively well-formulated opinions. Certainly, this knowledge appears to be basic. However, survey data indicate that the general population is not highly informed about politics either, which makes 'political ignorance' a more general issue as voters tend to make their choice based on team-like partisan allegiances rather than facts (Somin, 2010).

"I want to vote. I want to see how it plays out."

Intellectually disabled people generally vote at lower rates than the general population (Keeley, 2008). Certainly, several justifications can be advanced to explain this low turnout. However, King (2007) noted that people with ID aren't sufficiently informed about political issues. He also stated that there is a lack of election materials dedicated to helping this population better understand the election process. Besides, both families and service providers consider that this type of education is fruitless because individuals with ID are not politically aware (Bell et al., 2001; Redley, 2008). Throughout the interviews, the investigator attempted to assess the degree to

which these individuals understand the election process. This was achieved by asking the interviewees to describe the voting process and its purposes. The majority demonstrated basic knowledge of elections (94.7%).

First, they were able to define, in broad terms, the purpose of voting:

"We have to vote who we want to be president." — Sarah

"I know what it is. Voting for the new president." — Oliver

The majority of participants focused on the national level when answering these questions. However, three interviewees indicated that elections are also intended to choose local officials:

"Like the next president, the governor, the sheriff." — Sarah

This knowledge went beyond the candidates themselves and extended to the benefits of voting and choosing public officers. This included its effects on their personal lives. For instance, Emily, who was in her mid-thirties, stated that she votes for people who would give her a better job than the one she has. Chloe, on the other hand, said that *"people just need to find someone that doesn't raise stuff. It gets confusing whenever prices go up"*. Other responses covered several areas that could be improved through elections such as fixing sidewalks, having better paychecks, or reducing taxes.

Second, participants were asked to describe the voting process. As one would expect, those who never had a voting experience were unable to answer this question properly. Adam stated that he never thought about voting, *"I don't know what they do to vote. I've never done it."* But the majority of participants who voted at least once in their lives managed to recall their voting experiences in detail. For example, one interviewee highlighted the security measures that she had to go through. Another participant, Ethan, who was in his late fifties and said that he loves politics, stated, *"You just sign your name, register, some kind of a boring thing. I just marked it with the*

black marker. I can read. I did it myself". Sophie struggled to recall the tasks that she had to do at first, *"I can't [...] I had to stop at the table and get a ballot. I went to this little room [...] I had to pick a name."* Interestingly, several individuals employed the appropriate terms when talking about the voting procedure:

"I got my ballot and I went to one of the areas. I was coloring the circles, who I was wanting."

— Hannah

"They give us a ballot and we go to this booth thing and we vote." — Chloe

Other participants discussed a variety of topics related to voting such as polling stations, their encounters with election officials, or their voting choice.

Furthermore, I attempted to assess the degree to which candidates approach people with mental disabilities. As previously mentioned, intellectually disabled individuals are perceived by the literature as a marginalized group. And during election seasons, candidates try to convince the constituencies through various means and approach people from different social backgrounds. Thus, it would be interesting to see if people with ID are included in this process.

The interviewees were explicitly asked if they were ever approached by a candidate, party, or political campaign. The most frequent response related to the same local officer who visits the institution's facilities and usually talks with the clients. However, this observation cannot be generalized because this officer's spouse is one of the institution's employees and he also used to work there. This makes it a very particular occurrence that does not necessarily apply to other samples. *"I voted for [officer's name]. His wife works here. He comes here sometimes. We like him."*, said Oliver.

Apart from this isolated instance, 17 interviewees stated that they have never been approached by political actors. Amy, who was in her late thirties, stated, *"I was never approached*

by parties. I only hear about them on TV." Chloe also gave a similar statement, *"No, I was never approached by candidates. The only time I see them is parades, 4th of July or stuff like that."* Only two out of 19 participants indicated that they had such an encounter. Yet, it appeared to be a random contact rather than one that targets people with ID. *"We've had people coming to our door wanting us to vote for someone. I tell them I'll take it and look at it,"* said Adam

This demonstrates the lack of attention toward intellectually impaired individuals. Combined with their personal limitations, being marginalized would necessarily result in lower interests in civic life and political participation.

Previous research demonstrated that individuals with ID vote considerably less than the general population. For instance, Emerson (2005) noted that 31% of intellectually disabled adults voted in a general election compared to 72% of the general population. This further supports the previously discussed literature that suggests a gap between this group and the rest of society. In this project, participants were asked about their participation in elections. However, it is necessary to point out that the results obtained through these interviews might be influenced by the choice of the sample. The participants in this research were all clients of a service provider that, among other activities, places particular importance on civic life. The literature affirms that it is not generally the case for this type of institution (Bell, 2001). This unintended bias will be further developed in a later section that treats the impact of the institution on the sample's political behavior.

Overall, the results indicated high participation among interviewees. 89.4% of participants stated that they have voted at least once in their lives. 11 out of 19 individuals (57.8%) reported that they participated in the last election (the 2018 midterm election). Sadie, who was in her late sixties, said that she votes because she's American. Furthermore, several individuals exhibited an

interest in participating for different reasons. Emily stated that she votes because she "wants to see how it plays out." Another woman in her late thirties, Amy, said that she usually votes but would prefer doing it online. As to those who reported that they have never voted, they mentioned several reasons for their abstention:

"I've never voted. I never knew who to vote for. You never know what's going to happen from one to the next. I never thought about voting really." — Adam

"I don't vote at all ... I'm always busy working ... I don't know who to vote for. I don't know who's good and bad." — Harry

In regard to accessibility, several statutes have been enacted in order to provide suitable voting conditions for vulnerable people. The Voting Accessibility for the Elderly and Handicapped Act of 1984 places a requirement to provide accessible voting places for people with disabilities. This was later reaffirmed by the Help America Vote Act of 2002. Yet, several studies indicated that many polling stations are still inaccessible to people with disabilities (Ward et al., 2009). The majority of people in the sample indicated that they did not experience difficulties accessing the stations or while casting their ballots:

"The ballot was easy to read." — Nathan

"The words were a bit bigger than they were a time ago." — Amy

"The ballot paper was clear. I can see the names of who wants to be president" — Oliver

However, Daniel, who also suffers from severe short-sightedness, stated, *"I can only read big prints and they didn't have it at the courthouse."*

Moreover, intellectually impaired people often need help performing tasks in their daily lives and voting is no exception. Out of the 17 participants who stated that they had a voting experience, 13 individuals needed help while casting their ballots. Sarah, for instance, indicated

that she would start shaking if she goes by herself. This assistance seems to be needed even more when the intellectual disability is paired with a physical one.

"I've been on this walker for a while. I had both my hips replaced. My counselor helps me with voting." — Sadie

Considering that several interviewees were illiterate, help, in most cases, was provided by reading the ballot and specifying the person's choice. None of the participants indicated that this help came from election officials. They were all assisted either by their counselors or staff members from the institution.

"Someone helped me vote because it's hard to figure out." — Sarah

"[My counselor] goes in and tells me the names and I pick it out." — Sadie

"Someone helped me do it; one of the staff in our group home. She came to the booth to help me." — Edward

"Someone helped me read the ballot. [My counselor] did." — Sophie

"[The counselor] helped with most of it. She read off the questions and explained it to me a little bit better." — Hannah

In places where people with ID can still be deemed incompetent to vote, the justifications often revolve around their inability to formulate a conscientious and even methodical choice. Despite the prohibition of literacy tests on a federal level, several jurisdictions still employ them to assess legal capacity (Blood, 2014). To address these perplexities, the interviews included questions aiming at explaining the voting choice of people with cognitive limitations. Only three participants out of those who voted were able to formulate a coherent response. For instance, Hannah describes this process as follows: *"The way I look at it, I focus on what they stand for and if they will do a good job in the office. I just look at both sides and I compare them."* As to the rest

of the sample, several interviewees were unable to think of what motivates their choice. They stated that they do not know why they choose a particular candidate. Oliver said that he "just does it." And surprisingly, 40% of those who voted could not recall whom they voted for including those who participated in last year's election:

"I can't remember who I voted for. I can't even remember the president's name. (Investigator: How do you know which one to choose?) I don't know." — Oliver

"The staff here takes us sometimes."

The literature is clear on the topic of service providers and their impact on the political engagement of people with ID. Predominantly, such institutions often disregard civic activities. Voting, for instance, is not generally included in these services (Agran, 2013). The general tendency in the literature considers that these institutions are reluctant to include citizen education in their programs. Service providers may think that people with ID are unable to make informed political decisions (Schriner et al., 2000); which explains the lack of encouragement to participate in civic life. In a study conducted by Pavey (2003), special education teachers were asked to rate curriculum activities that include several areas. Voting was rated among the least important areas which further affirms previous literature.

However, the institution that was contacted for this work appears to place particular significance on this aspect of their clients' lives. *"We ask them if they want to register to vote."*, said one of the counselors. She also explained that they check on an annual basis to see if someone wants to register. Furthermore, transportation is provided to polling places during election seasons. The counselor noted that they go in groups or individually and that they go to voting places early to make it less intimidating. Hence, the institution where this research was conducted is an outlier.

This particularity, however, does not make the findings less valuable. To the contrary, it shows the positive impact that service providers could have on people with ID and their civic lives.

Throughout the interviews, one could discern the impact of this service provider on individuals' participation. Almost every participant indicated that they were asked by staff members if they would like to vote. *"They ask us who wants to go early voting,"* Sarah noted. Another participant, Harry, who said that he does not vote at all, stated, *"I'm always busy working. I'm a janitor full time. They asked and I told them no."* It also appears that staff members that the counselors generally ask individuals collectively and not on an individual level.

"The counselors ask everyone at once. They'll sit out there and ask who wants to go to vote." —

Adam

Transportation is also provided by the institution. People are asked if they would like to vote and they are taken to polling stations. 11 out of the 17 participants who vote reported that they usually go with counselors or staff members to cast their ballots. Transportation is often seen as one of the barriers that lower voter turnout among the intellectually disabled (Schur et al., 2002). Several individuals in this sample had mobility impairments. This further confirms the positive impact that service providers could have if they implement such initiatives.

"I went with the people in my group home. Some staff here took me there. They asked me if I wanted to go and I said yes." — Oliver

"They take us places all the time like Walmart. They try to find stuff for us to do so that way we don't just sit there and do nothing. And sometimes people who want to vote they take them and bring them back to workshops. Every time we go we have to sign off and sign in." — Adam

Figure 1: Voting rates by type of accommodation.

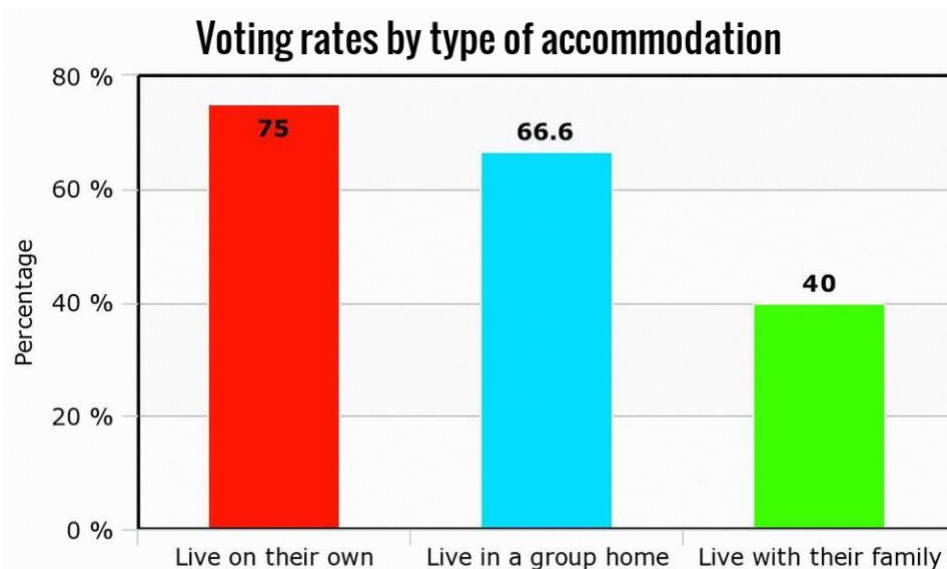


Figure 1 illustrates participation rates in the 2018 midterm election by type of accommodation among participants in this study. It shows that people are more likely to vote if they live on their own (75%) or in a group home (66.6%) compared to those who live with their families (40%). Participants stated that group homes are organized by the institution and that it is a form of collective supported living. One should also point out that most people who stated that they live on their own also indicated that the institution renders services to them as well. Thus, one could see the positive impact of including civic activities in the programs of service providers. The high turnout among people in this sample can be explained not only by the role of the institution but also by the 'peer pressure' effect that it creates. Having people who vote in one's circle is regarded as an incentive for participation (Gerber et al., 2008; Levine and Salvatore, 2016). Hence, the findings also indicate that individuals with ID are more likely to participate when their peers vote as well.

Besides, voting is generally discussed and explained by the counselors before going to the stations. Adam continues to say that their counselors *"talk about politics a lot of the times."* and

that they would tell them "a little bit about voting" before casting their ballots. *"We talk about it before we go."*, said Sarah.

Moreover, several responses indicated that politics is a frequently discussed topic within the institution.

"[The counselor] talks to us about this when we do the downtime class." — Amy

"[The counselor] talks to us about what's going on sometimes." — Harry

The positive impact of citizen participation on people with ID is observed in this study. More broadly, the literature considers that such education plays a role in increasing political engagement, which was the case of adolescent students for example (Hooghe and Dassonneville, 2012).

Respondents also indicated the political preferences of the counselor that usually discusses politics with them. One of the major reasons invoked to justify disenfranchisement laws is the vulnerability of people ID; which makes them susceptible to influence. Thus, I thought it would be interesting to verify whether interviewees are affected by their counselor's opinions. Out of those who disclosed their voting choice or preferences, 64.2% of them had opinions that align with the views of the counselor. Furthermore, individuals were more likely to have a voting choice that aligns with their counselor's if they voted with the institution (66%) compared to those who did not (50%). Again, these observations are not unique to people with ID. Authority figures tend to have an impact on people's political attitudes such as parents (Tedin, 1974) or teachers (Kane, 2012).

"I asked my dad who to vote for"

As the previously discussed literature suggests, families often have an influence on the political engagement of people with ID. Previous research attempted to study the interaction

between political socialization and family relations. For instance, it was found that young individuals were likely to adopt the political preferences of one of their parents (Shulman and DeAndrea, 2014). Families can generate incentives to citizen participation among individuals with but could also deter them. People with disabilities can be rejected by their family members and, in communities that have traditional leadership roles, excluded from holding such positions (Baffoe, 2013). Other studies confirm these assertions and consider that exclusion from community activities for people with disabilities starts at the family level (Mbibe, 2013). Family members, along with caretakers, are seen as gatekeepers. They often take informal gatekeeping decisions that impact the lives of people with intellectual disabilities, including its civic aspect. For instance, they can omit civic education based on the belief that the person is unable to participate (Darragh et al., 2017).

The sample in this study, however, included mostly people who are their own guardians. This certainly has an impact on the level of influence exerted by family members. First, I attempted to assess this influence on voter turnout. Out of those who voted in the 2018 midterm election, 77% stated that at least one of their close family members also participated. These findings confirm previous behavioral studies saying that having active voters in their close circles is an incentive for people with ID (Keeley et al., 2008).

Interviewees noted that politics is not a discussed topic among their family members. *"I don't discuss politics with them. That's an illegal topic for them to talk about. I don't want to be yelled at."*, Amy said. This behavior should not be necessarily interpreted as an intentional exclusion. Participants' responses indicated general political apathy among their family members, which aligns with the behavioral literature that observes an increasing disinterest in politics (Curato and Niemeyer, 2013).

Qualitative evidence from the majority of interviews shows that families do not significantly intervene in the civic lives of participants. In most cases, family members were either supportive or indifferent as shown by the different responses given by interviewees:

"I told my brother I'm going to vote. He said it's up to you. It's your life, not mine." — Sarah

"[My brother] knows when I go to vote. He said okay. But it's none of his business who I choose." — Sadie

"I didn't tell them before voting. I told them afterward. They didn't say anything. My dad says it's your own choice." — Hannah

"My sister votes. I told her I'm going to vote and she said go ahead." — Sophie

Others even discussed the political views of their family members and whether they align with theirs:

"My family is half Republican and half Democrat. I'm independent. I just go vote for whoever I like." — Emily

On the other hand, two interviewees stated that they were either influenced by family members regarding their voting choice or even asked to change it. For instance, Daniel noted that he picked a candidate because his father picked him, *"I asked my dad who to vote for."* Daniel said that he was uncertain about his choice and decided to vote for the candidate that his father picked. In addition, Ethan said that he was asked by family members to change his voting choice, *"My step sister and brother wanted me to change. Before the courthouse, they asked me to change. They told me 'switch'. They said Clinton is not the right one. I had no idea, I was confused."* These two cases, however, constitute outliers in this sample. Most participants indicated that their family members do not have a say in their voting choice.

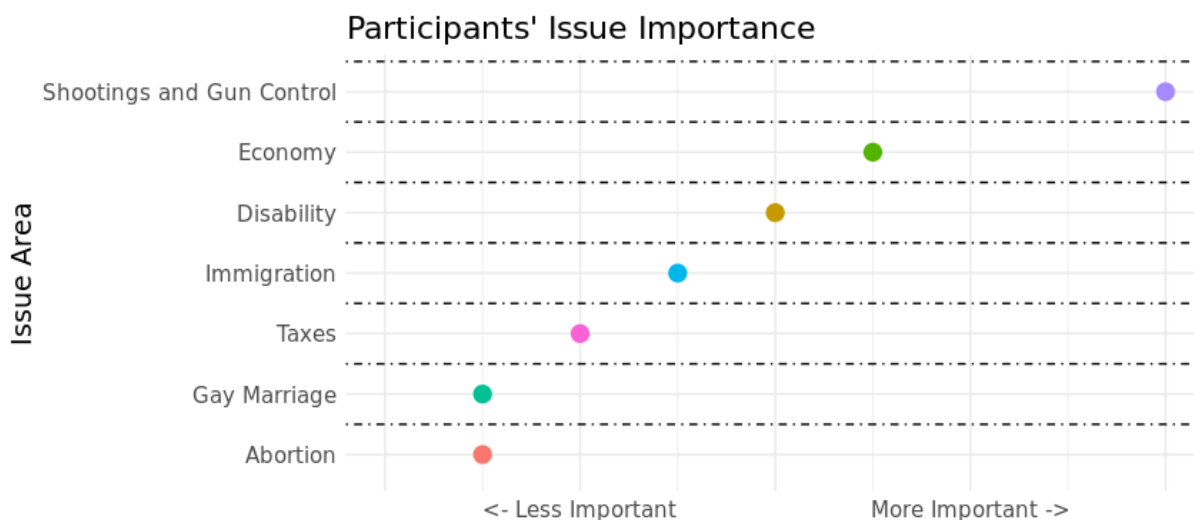
"I would like to have respect."

Issue importance is another concept developed by the literature that can also be an indicator of political participation. Previous studies have employed this term to explore policy areas that people are interested in. It is often defined as "the degree to which a person is passionately concerned about and personally invested in an attitude (Krosnick, 1990)." Krosnick's works are among the most notable on this topic. He considers that issue importance interacts with other key variables related to citizen participation. For instance, he asserts that perceptions of candidates and vote choice are strongly related to policy attitude importance. When people make decisions, including the ones that are related to politics, they do not usually take into account the entirety of relevant factual information (Iyengar and Kinder, 1987). Instead, decisions are often based on the most accessible pieces of information that come quickly to one's mind (Miller and Krosnick, 1996). These considerations render important attitudes "more cognitively accessible" making them more likely to be used as criteria to evaluate political actors (Krosnick, 1990). Moreover, these attitudes tend to be enduring despite being mostly determined by short-term factors (Berent and Krosnick, 1995). Political actors often employ these attitudes to attract the electorate. Considering that people often focus only on a handful of issues (Wlezien, 2005), parties and candidates tend to highlight certain matters to differentiate themselves from others (Ray, 2003).

Tidyttext, an RStudio open-source package, was employed to study the issue preferences of this sample. The input text (the participants' responses) was analyzed using this data mining process. A list of keywords was generated and sorted based on its frequency within the content of each interview. These keywords were later assigned to several categories corresponding to different issue areas. This approach was preferred over explicitly asking respondents about the

importance of each issue. Analyzing the content of their responses was deemed more effective in divulging their real attitudes towards issue areas.

Figure 2: Participants' Issue Importance.



The above figure summarizes the output generated by the text mining process concerning all interviews. Issue areas were identified and sorted based on the number of interviewees that mention them.

Interestingly, issues that are directly related to people with ID were not the top priority of participants. As the figure shows, disability issues ranked third among these areas. These findings align with the previous, more general, literature. Lau and Heldman (2009) asserted that self-interest does not guide people's political preferences. Instead, these attitudes are often determined by abstract symbolic beliefs. Four out of 19 interviews contained responses that address issues related to disability. Amy, for example, said that she would like politicians to become more informed about individuals with learning disabilities and their needs such as providing large-print versions of administrative documents. She also expressed her discontent regarding the terms used to refer to people with ID: "[...] also not having people diagnosed as mentally retarded. I don't

like that word. I would like to have respect." Emily, a participant who complained about political actors saying that mentally disabled people are to blame for shootings, stated, *"He said that mental people need to be locked up. He blamed them for El Paso shootings."* Hannah also reflected on this issue as she stated, *"They're trying to say that people with disabilities are the main reason for all the violence. It makes me feel horrible."* On the other hand, Adam pointed out the importance of providing public financial support to institutions that attend to people with ID. *"This place is supposed to make things easier for us. And for a while, people were thinking that the funding from the government was going to go bad. If funding goes down, we lose this place. We'll need to find other jobs. I think the state does the funding."*, Adam said.

It was also apparent that participants' attitudes were influenced by recent events that occurred when these interviews were conducted. As demonstrated by the previous figure, shootings and gun control were the topics that interviewees discussed the most. Eight interviews contained responses that reflect on these issues. These responses indicated not only that participants are aware of what happens in the country but also that they have attitudes toward these matters.

"I think everybody should have the right to have a gun. They should know how to use it properly

[...] These kids need to know how to control it a little better." — Adam

"I was sorry to hear about El Paso, Texas. Shootings, mass shootings. They killed ten people in

El Paso, Texas. And another in Ohio." — Nathan

"They need to take the guns off the shelves. These kids start shooting; it can happen anywhere.

Two years ago, they locked all the doors to the high school because someone brought a gun in.

We couldn't go anywhere. The police told us we can't go anywhere." — Sarah

Five interviews contained references to economic issues. These responses revolved mainly around problems that individuals face in their daily lives such as prices and wages.

"They could do something like giving us more than a three dollars Christmas bonus. Well, we all could use more than that, especially when you're very hungry; to get stuff out of the vending machine." — Amy

"Groceries keep rising and going down. I say make your mind president. How are we going to pay rent, phone bills, cable bills? How are we going to pay for everything? Prices affect me because when we go grocery shopping, I'm like I'm not getting this coffee." — Sarah

Three interviewees talked about immigration and developed their thoughts on the issue. Their responses either originated from personal experiences, such as having immigrant friends, or from media coverage.

"[...] People won't be able to cross; to get a better life. He wants to keep the immigrants out. He thinks that they're bad people. They're not because if you look at the U.S., everybody was an immigrant at some point. Everybody came from somewhere else. So, if he builds the wall, he's diminishing what the United States stands for." — Hannah

"As long as they come here legally, I don't mind. They want to escape their own problems? Fine, let them in. They want to be here, they want a better future, escape the killings. I have Mexican friends. I don't mind them coming in legally." — Emily

"[The president] built a wall in the south. That's fine to keep all the people outside. I like that. It keeps them away from Illinois. There are bad people on the other side of the wall. I heard him talking about it on the news." — Oliver

Gay marriage was also addressed by one of the participants. Oliver, whose brother is gay, stated, *"I don't like the [president] we have now. He's done some bad stuff. He's trying to get rid*

of gay marriage. I don't want him to. My brother is gay." Other discussed issue areas covered taxes and abortion.

"Some politicians take some of your taxes. They take it out of our paychecks. My paycheck would be humongous if they didn't take taxes out of them. I have no idea how the governor is using them." — Chloe

"People kill their babies before they're born. I hate abortion. I don't like people doing it. Some people want it out of their belly before it's time for it to come. Some people don't want their kids; they just want to throw them out. I heard it in my church. You're giving up a kid that you have in your stomach." — Sophie

Overall, the responses reflected that participants are not different from the general population. A survey conducted by the Pew research center indicated, for instance, that economy and security are among the top priorities of the American public⁸.

"People need to hear our voices loud and clear."

Previous sections indicated that not only are participants relatively knowledgeable about politics but that they also participate in elections at high rates. These observations implicate that they have party or candidate preferences. Thus, exploring the patterns of their partisan profile would be insightful. Partisanship is seen as a powerful indicator of civic participation that influences political attitudes (Gerber, Huber, Washington 2010). Dancygier and Saunders (2006) asserted that partisanship "is an active force shaping how individuals evaluate and interact with the political world." Partisanship does not only persist across the life course (Green et al., 2002), but also has a strong correlation with salient political opinions (Bartels 2000). Moreover, people's

⁸ "Public's 2019 Priorities: Economy, Health Care, Education and Security All Near Top of List." 2019. Pew Research Center for the People and the Press. <https://www.people-press.org/2019/01/24/publics-2019-priorities-economy-health-care-education-and-security-all-near-top-of-list/> (October 31, 2019).

party affiliation reflects their political attitudes and causes them at the same time (Norrande and Wilcox 1993). The Pew research center conducted a survey that explores the political profile of Americans with both physical and intellectual disabilities. It suggested that disabled Americans are not different from the public as a whole "in terms of party affiliation and their distribution across the ideological spectrum."⁹

Participants were asked questions that seek to explore both their partisanship and their knowledge about political actors. Interviewees had different impressions about parties. Emily, who says that she is a full Democrat, noted, *"They need to approach people and ask them what they can do for them and not ask us what we can do for them."* Nine out of 19 participants were able to correctly differentiate between Democrats and Republicans. But this does not entail that the other individuals were uninformed about parties. Most of them had several thoughts on this topic and, in some cases, managed to recall prominent figures from each side. But these responses included several inaccurate factual information, which explains the previous observation. Chloe, talking about her husband and herself, stated, *"I think we're democrats but I'm not sure. I don't know if we're democrats or the other one."* Furthermore, most interviewees reflected on their party affiliations and, in some cases, the reasons behind them. Their responses demonstrated a certain degree of familiarity with the concept of parties. They also showed that people ID, similar to the general public, have personal attitudes toward parties. Several individuals said that they are either Democrat or Republican, while others stated that they are independent.

⁹ Igielnik, Ruth. 2016. "A Political Profile of Disabled Americans." Pew Research Center. <https://www.pewresearch.org/fact-tank/2016/09/22/a-political-profile-of-disabled-americans/> (October 31, 2019).

"I can't even remember if Bernie Sanders is Republican or Democrat. But he's actually one of my favorites. I know Joe Biden is a Democrat because of Obama. I'm basically an independent voter. I don't have a favorite party. I vote for who I think would be best." — Hannah

"I love democrats. I can understand them more than Republicans. They could do a better job for me." — Amy

"I don't like democrats. Republicans are good people. They keep cities safe." — Oliver

"People have their own opinions like anyone else. I don't really like one more than the other." — Adam

Citizen participation also includes aspects other than voting or partisanship. This work seeks to go beyond the existing literature and explore the civic lives of people with ID from different perspectives. Previous studies have indicated that cognitively impaired individuals are also less likely to participate in other forms of political activity such as contacting taking part in campaigns, contacting representatives, or attending political meetings (Schur et al., 2002). These suggestions were affirmed by participants in this study who all stated that they have never attended political meetings or contacted elected officials. For instance, when asked about these activities, Amy stated, *"Sometimes the representatives don't listen to us. So I don't really go see them."* This also aligns with Schur's (2013) findings indicating that people with disabilities are more likely to have a negative perception of government and elected officials compared to the rest of the public. As to political meetings, Sarah said that she avoids such activities due to her learning disability, *"Sometimes my words would get mixed up, So I don't go to meetings."*

Mobilization and self-advocacy were also among the discussed topics in the interviews. Previous research indicated that the education of people with disabilities does not generally include self-advocacy (Izzo and Lamb, 2002). Yet, it is seen as an effective way to empower these

individuals, improve their engagement in civic life, and offer an opportunity to resist against stigmas (Spassiani and Friedman, 2014). It also produces senses of community, identity, and disability pride (Caldwell, 2009). However, most interviewees indicated that they have never had such experiences. When asked about mobilization and self-advocacy, Adam stated, *"No, nothing like that."* Only two participants mentioned their participation in a protest in the state's capital when the institution was at risk of losing funding.

"I participated in one protest in Springfield. It was about money, the budget in Illinois. I was asked if I would like to go by one of my friends here at [the institution]. I said yes because people need to hear our voices loud and clear. I don't know who organized it. We took a van with [the institution]." — Amy

"We went to Springfield in May with the Group. We went up there and we participated in that. It was about clients in [the institution] and parents." — Nathan

"I saw it on TV."

Sources of information are usually strong determinants of people's political behavior. Political awareness of people with ID, for instance, was an area that this study focused on. The literature suggests that patterns of media use are likely to increase this awareness (Eveland et al. 2000). Access to sources of information such as news affects citizen participation (Gentzkow et al. 2011) and even political views (Della Vigna and Kaplan 2007). But the general literature also points out that these effects are ambiguous and vary across demographics (Mullainathan and Shleifer 2005). This research attempted to explore participants' sources of information. 18 out of 19 interviewees indicated that television and newspapers are their primary sources of information. They also stated that they access these outlets both in their homes and inside the facilities of the institution.

"I saw it on TV. I watch it in my group home. It's always me falling asleep in front of the TV." —

Amy

"Grandma watches news 24/7 so I watch it too. It's on all night long. I wake up and it's news on

TV." — Emily

"I also read newspapers whenever I can get my hands on one." — Hannah

Previous studies also highlighted that disabled people are less likely to have access to computers and the internet, which restricts the possibility of being involved in web-based political activity (Kaye, 2000). This was affirmed by participants' responses as only three out of 19 stated that they get political information from online sources.

"Facebook has a lot of stuff on it. I usually use Google to look stuff up. All the politics stuff shows up on my phone." — Adam

"I see the news on wifi. I have wifi at home. I watch Fox if I get it on wifi. I remember seeing the hurricanes and stuff like that. It tore people's houses up." — Harry

"I follow all the good politicians on Twitter." — Hannah

Furthermore, discussing political issues with others can stimulate "a sense of political engagement" (Galston 2001; Gastil and Dillard 1999). In this context, participants indicated that their counselors usually discuss politics with them. They stated that they keep them updated about political events and share their opinions.

"Sometimes our counselors read stuff from their phones about what's going on and what people in politics are doing. I listen but I don't really like this stuff." — Chloe

"I talk politics with [my counselor] because she used to be on the county board. She's a democrat. We mostly talk about it in the lounge." — Hannah

"[The counselor] talks to us about this when we do downtime class. She tells us what's in the news today." — Amy

Conclusion and discussion

This project sought to explore the civic lives of people with intellectual disabilities. An overview of the literature demonstrated that cognitively impaired individuals, as a disadvantaged group, are considered unable to participate and make informed decisions (Schriner et al., 2000), and often lack the resources to do so (Whittell and Ramcharan, 1998). In-person, semistructured interviews were conducted with cognitively impaired individuals, recruited using convenience sampling, to explore several aspects of their civic lives. Traditional methods of content analysis, such as constant comparison, were combined with the qualitative analysis software, ATLAS.it, to identify different themes. RStudio was also used to explore the issue with a statistical approach and to study patterns across the interviews via text data mining.

The findings indicated that participants are generally aware of political events and that they can form relatively informed attitudes toward them. Their responses indicated a level of knowledge that is not significantly lower than that of the general population. They also demonstrated an interest in participating in elections and a basic understanding of its process. However, they recognized their need to be assisted while casting their ballots due to their disabilities. Furthermore, contrarily to what the existing literature suggests (Agran, 2013), the service provider that was approached for this study places significant importance on citizen participation. The findings demonstrated the positive impact that these institutions could have. Voter turnout and political interest were particularly high among the sample due to this factor. As to family members, the responses did not exhibit a major influence on interviewees' civic lives. In most cases, family members were either supportive or indifferent. This contradicts the general belief that people with

ID are easily manipulated, which is often used to legitimize disenfranchisement laws (Holland et al., 2011). The interviews also reflected a similarity between people with cognitive impairments and the nondisabled public regarding issue preferences, partisanship, and sources of information.

As to its implications on policymaking, this analysis showed the need to promote citizen participation among people with ID. Considering their ability (and willingness) to engage in public life, general statutes that restrict their activities should be turned into a case by case approach. Moreover, political actors need to address this population as the findings showed that people with ID are usually neglected and excluded from the democratic process. The interviews also proved the benefits of including citizen education in the programs of service providers and encouraging civic activities within these institutions. Besides, the findings highlight the importance of including these individuals in community life. For instance, a 'peer pressure' phenomenon was observed where individuals were more likely to vote if they have active voters in their circles such as friends, family members, and caretakers.

A major strength of the present project was relying on direct input from people with ID instead of depending on other stakeholders and proxies (Sigstad, 2014). Obtaining personal accounts and experiences from intellectually impaired individuals is an important step toward understanding the patterns of their civic lives. This approach had a positive outcome as this analysis explained their behavior. It also covered several aspects of citizen participation as opposed to previous research that solely focused on voting.

One of the limitations of this work is the use of convenience sampling. This method can have an impact on the external validity of the findings and their generalization. However, this approach was deemed necessary due to the lack of access to such a demographic. Furthermore, the

majority of participants in this study did not have legal guardians and they were all affiliated with an institution. Thus, the accuracy of these conclusions can vary under other circumstances.

Future research should address these sampling issues. Including individuals from different backgrounds and having various living conditions will be beneficial to reach more generalizable findings. Having bigger samples will also serve that aim. Further, combining input from both people with ID and other stakeholders can help in obtaining more comprehensible input that covers all aspects of the issue. Research should also tackle the question using an intersectional approach. It will certainly be useful to study the impact of several variables such as age, gender, race, socio-economic background, and level of disability. Finally, assessing the role of the socialization process on people with ID will provide valuable insight as well.

Another issue that should be addressed is the lack of survey data related to people with cognitive disabilities. Several research centers include disability in their questionnaires. However, these questions do not distinguish between different types of disabilities. For instance, the Maxwell poll¹⁰ asks respondents about emotional and mental disabilities in one question. Whereas these types of disabilities are different as the former refers to processing feelings and the latter to cognitive and learning limitations¹¹.

Overall, this project is one of the few that sought to get direct input from intellectually disabled people. It covered several aspects of their civic lives and attempted to address the issues that are commonly related to their citizen participation. The findings generally point out the need to include people with ID and promote their civic engagement.

¹⁰ “Campbell Public Affairs Institute: The Maxwell Poll.” 2013. The Maxwell School of Syracuse University. https://www.maxwell.syr.edu/campbell/programs/The_Maxwell_Poll/ (October 31, 2019).

¹¹ Herron, Andrea. 2018. “The Emotional and Mental Aspects of Well-Being.” WebMD Health Services. <https://www.webmdhealthservices.com/2017/07/12/the-emotional-and-mental-aspects-of-well-being/> (October 31, 2019).

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